

Macro-Level Consumer Preferences Discussion for 3/19/10

1. Straw Proposal: Eligible providers (EPs) and hospitals engaging in one-to-one disclosures of data pursuant to the Stage 1 requirements of meaningful use are not required to satisfy any additional prior patient authorization requirements beyond those that already exist in law (or that that the EP or hospital may adopt as a matter of organizational or institutional policy). EPs and Hospitals should be transparent with patients about data access, use and disclosure, and particularly when data is disclosed outside the organization/entity.

Rationale:

- Covered by existing law
- Providers/Hospitals still required to navigate privacy rules (including rules regarding sensitive data) and patient requested preferences.
- Decisions about whether data is pushed to another provider, hospital or health plan – or to a public health authority - and how much data is pushed – remain with the trusted holder of the data, who has the closest relationship to the patient and can be held accountable both by the patient and legal authorities.
- In most instances, patient is at least aware of the transfer – basic transparency about when and where data is being sent will help ensure this is the case. (For example, when patient is being referred to a specialist, referring physician can let the patient know that relevant health information for his or her care is being sent to the receiving provider.)
- Just applies to eligible providers and hospitals for Stage 1 of Meaningful Use (not other data holders, including those also covered by HIPAA).
- Facilitates NHIN Direct model – where EPs and Hospitals as data holders push data to fulfill meaningful use, either in a one-to-one exchange or through a trusted intermediary. In either case, the decision to disclose – and how much to disclose – remains with the EPs and Hospitals.
- Meaningful use criteria cover exchanges for treatment, insurance eligibility, public health reporting, and quality reporting (and with respect to the latter, the reports are in the aggregate).
- Imposing additional consent requirements just for meaningful use for direct one-to-one exchange could be disruptive to care processes and provides a disincentive to adopt Certified EHRs because it's an obligation imposed on EPs and Hospitals that doesn't apply to other covered entities.

2. Next phase of discussion – begin on 3/19 and continue on 3/25

- Policies with respect to an ability of providers and hospitals to query and “pull” health data from another record, potentially without the record holder or the patient knowing
- Scenario more likely when a “network” is involved – for example, a RHIO or HIE.
- Existing law is far less clear (or at least didn’t envision these models), and thus the privacy implications of “pull” models are more difficult – and important – to resolve.
- NCVHS recommendation re: right of individuals to opt-out applies to having information accessed via “NHIN” (at a time when that term assumed a network of networks approach)

QUESTIONS TO CONSIDER:

- How to define when such choice applies – e.g., what qualifies as a network to which choice should apply?
 - Define by functionality – for example, ability of providers to query a database and pull data from another record (presumably pursuant to a participation agreement that binds entities to certain rules, but not always with the knowledge or consent of the initial data holder or subject of the data).
- Potential macro choices:
 - None
 - Right to opt out – prospective only
 - Requirement to opt-in
 - All in or all out – or on an organization/office basis? (works only with federated models?)
 - FOR LATER DISCUSSION – choice based on type of data
- Where choice applied:
 - For data to be made available/uploaded (and by what type – basic directory information only or also clinical data?)
 - For data to be accessed/downloaded
- Distinguish by purpose for which data is accessed?
 - Treatment?
 - Emergencies?
 - Payment?
 - Care Coordination/Management/QI? Secondary Uses?
 - Allow networks to decide?
- How apply?
 - Allow states/networks discretion to decide

- Require process that includes consumers?
 - No consent needed if uses limited to treatment and lawful public health reporting
- Develop set of recommendations/best practices for networks/states to use
- Requirement for states/NHIN (what about states with RHIOs/HIOs that today do not have any choice policy?)
- If requirement, how enforce?
 - BA agreement requirements
 - Federal funding condition (ONC grants)